

Newborn Screening Update

Michigan Newborn Screening Program

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Introducing

Bill Young began his position as the Newborn Screening Program Director in 1979. His role is to manage the Newborn Screening follow-up and Medical Management Program. This includes assuring that a system is in place to rapidly screen and/or re-screen all infants born in Michigan. In addition, he is responsible for contracting with medical care and laboratory specialists to provide confirmatory diagnosis and medical management for affected newborns.

Bill received his PhD in Human Genetics from the University of Minnesota in 1973. Prior to his position with the state, Bill was a Geneticist at the Minnesota Department of Public Health for 3 years and an Assistant Professor in Genetics at the Eastern Virginia Medical School for 5 years.

Bill was born in Vineland, New Jersey, and raised in Philadelphia, Pennsylvania. He has two children and six grandchildren.

Feel free to contact him with questions or concerns regarding the NBS program. His phone number is 517-335-8939. His e-mail address is youngw@michigan.gov.

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When is the best time to obtain the initial NBS specimen?

Every effort should be made to screen the newborn between 24 and 36 hours of age. If a specimen is drawn before 24 hours of age, some disorders that are present may not be detected. If the blood is drawn after 36 hours of age, there could be a life-threatening delay in providing care to an affected infant.

The initial newborn screening specimen should be obtained, even if the baby is less than 24 hours of age, in the following circumstances:

- The family desires an early discharge (before 24 hours of age),
- The baby is being transferred from one facility to another,
- The baby is to receive a transfusion of red blood cells, and,
- The baby is to receive the administration of TPN.

In the above instances a repeat newborn screening specimen may be required. Follow the recommendations for obtaining a repeat newborn screening specimen that are noted on the Early Specimen Notification Report from the Newborn Screening Laboratory.

Initial newborn screening specimens that are obtained after 36 hours of age will be monitored and included in future Quality Reports that are sent to the hospitals and midwives.

It is important to note that, in the case of transfers and early discharges, the birth hospital has the responsibility to ensure that the initial newborn screening specimen was obtained and received by the Newborn Screening Laboratory. In addition, the submitter is legally responsible for the completeness and accuracy of the information noted on the Newborn Screening Card.

This information is available as a part of the Online Newborn Screening Course and on the Newborn Screening Webpage. Contact Midge McCaustland if you have questions or concerns.

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A Few Reminders ...

Newborn Screening Webcast from Children's Hospital of Michigan...

Title: Expanded Newborn Screening: Changing the Face of Inborn Errors of Metabolism

Date: May 19, 2006 Time: 12 noon to 1:15pm

This presentation will:

- Outline the history and future of newborn screening (NBS) in the State of Michigan
- Explain how tandem mass spectrometry has revolutionized NBS
- Provide an overview of metabolic disorders included in Michigan's expanded NBS panel
- Describe services offered by the Children's Hospital of Michigan Metabolic Clinic

To register, call toll-free 1-866-1247 or visit MIGeneticsConnection.org and click on the "Expanded Newborn Screening" box for further instruction.

This educational opportunity is sponsored by Wayne State University School of Medicine from Children's Hospital of Michigan for physicians and other health care professionals providing primary care to children.

Expanded newborn screening...

The newborn screening laboratory screens all infants for forty (40) disorders. Effective May 1, 2006, all disorders will be included on the notification of screening results.

Adequately sealed envelopes...

Instances of open envelopes containing the completed NBS cards arriving in the state NBS lab have been reported. Please remember to check to ensure that the envelope is properly sealed prior to mailing. It may also be beneficial to maintain a list of the infants whose cards are included in each envelope to ensure proper tracking if an envelope is received open at the NBS lab.

Completing the NBS card...

Remember ... it is extremely important that each space on the NBS card be completed accurately. Misinformation or missing information may result in a life-threatening delay in providing care to an affected infant.

Remember ... correctly document the date and time of birth, birth weight, and gestational age of the infant.

Remember ... document the date and time the NBS specimen was obtained, as well as, the initials of the person obtaining the specimen.

Remember ... ask the mother to verify her correct address, phone number, and social security number prior to documenting this information on the NBS card.

Remember ... ask the mother to identify a physician/clinic who will provide care to her infant following discharge home from the hospital. Be sure to document the correct physician/clinic name and phone number on the NBS card.

Remember ... fill in the appropriate blocks on the NBS card, even if your hospital does not have an NICU/SCN or administer TPN/blood transfusions.

Remember ... fill in the appropriate blocks on the NBS card for heritage and race.

When the infant is being placed for adoption, etc. ...

If the infant is being placed for adoption or is a "safe haven" baby, the name of the person or agency that has the responsibility for authorizing care and treatment of the infant may be documented on the NBS card in the space where the mother's name and demographic information is requested. The name and demographic information of the adoptive parents may also be entered if this information is known.

If there is knowledge that the last name of the infant on the birth certificate is different from the last name of the mother, it is helpful to document the infant's correct name on the NBS specimen card.

A Mother's Story

The last time I was asked to write our family story, my daughter Nicole, who has Classic PKU, was two and I was 6 months pregnant with our second child. Today our family includes Nicole 11, Mitchell 8, Audrey 5, a cat named Boo, and a bird named Kiara, oh and I must not forget two Hermit Crabs. Nicole still holds the special spot as the only one with PKU, although her sister declares that she wishes she had PKU because then she could lick the cake batter. You see, high phe cake batter has raw eggs in it making it unsafe to lick, but low phe cake batter does not have eggs, making the ever-irresistible bowl, and spatula safe and enjoyable. This only proves my point, that in every situation good can be found.

Nicole was born on March 23, 1995. Five days later she was diagnosed with Classic PKU. My first feelings were ones of guilt and fear; however, I was determined to provide Nicole with the best care possible. That meant learning, learning and more learning and now 11 years later I am still learning. I read every article I find and attend every camp, conference and cooking class that I possibly can. As Nicole grows and matures, I make sure that she is included in everything. I truly believe that the key to overcoming fear and achieving any goal is to educate yourself and create a foundation of families that you can rely on for support and encouragement.

Because Nicole has Classic PKU, she must adhere to a strict diet. FORMULA FIRST is our motto. Our goal is to be compliant with the diet and strive to achieve blood levels that are acceptable. She starts off each day knowing that she can only have 250 mgs of PHE, so she makes choices about what she will have for her meals and snacks. She also is beginning to realize how important it is to plan ahead for special treats, such as popcorn or French fries. Every day she manages to do this, while still playing soccer, enjoying rock climbing, sleepovers and being a wonderfully typical preteen.

Nicole has dreams to one day become a medical researcher for metabolic disorders and to discover new and innovative ways to produce foods that are low in phe. I look forward to watching Nicole realize her true potential and remain a productive and healthy individual.

Thanks to Nicole's mother, Becky, for sharing her story.

Announcement...

Effective February 1, 2006, nurse participants who complete the entire Michigan Newborn Screening Online Course, submit the posttest, evaluation and required demographic information will receive a certificate for 1.2 contact hours. This continuing nursing education activity was approved by the Michigan Nurses Association, an accredited approver of nursing continuing education by the American Nurse's Credentialing Center's Commission on Accreditation.

Since we did not receive notification of the awarding of contact hours until the middle of March, we are attempting to contact those nurses who meet the above requirements so that their Certificate of Contact Hours can be sent to them. If you are one of those nurses please contact Midge McCaustland by e-mail so that she can verify your completion of the course, obtain the appropriate demographic information, and send out your Certificate. Midge's e-mail is mccaustlandm@michigan.gov. Her phone number is 517-335-8588.

Nursing Contact Hours are also available for the "live presentation" of the course.

Information to share ...

Welcome Baby With Loving Hands

Nervous about childbirth? There are many unknowns. Certified Doula's can help. They offer emotional and physical support to help you and your significant other bring your child into the world.

Doula services offered include:

Use of a BIRTHING BALL This ball can help relieve back labor. Along with the help of gravity, it may also help progress the labor process.

WHIRLPOOL TUB What better way to relax than with a nice warm bath? The jets help to relieve the stress in the back while the warm water helps relieve the pressure on the belly.

HOT & COLD COMPRESS This may help with the little aches and pains in both the back and belly.

ONE ON ONE PHYSICAL & EMOTIONAL SUPPORT During the entire labor process a doula is there for you. She helps you to understand the progression of labor and what you are feeling. She's there to keep you and your support person informed along the way.

SUPPORT PERSON INTERACTION Our doula's encourage your support person to help you in your labor process. They work hand-in-hand with them to help them be involved as labor progresses.

SOUND & MASSAGE THERAPY Our doula's offer back massage and sound therapy such as soothing music as another form of relaxation. This helps to keep you calm and as relaxed as possible.

BACK & HIP COUNTER PRESSURE This technique helps to relieve stress from your hips and back by applying a small amount of pressure to these areas. This also helps in the progression of labor.

At Hillsdale Community Health Center doula services are a part of the package. Our doula's are available around the clock. They are ready to offer you this FREE service to make childbirth a pleasant experience.

Special thanks to Helena Jagelski and Amy Stoll from Hillsdale Community Hospital for sharing this information!

Information Sharing ...

Hospitals and other providers are invited to share information on their practices, policies, procedures, and experiences in an effort to improve the NBS process. This information is not to be considered a "requirement" of the NBS program. It is merely a "sharing of ideas" that you may choose to evaluate for use in your facility. If you would like to contribute an idea to share, please e-mail the information with a contact name, phone number, and permission to include the information in the NBS Update to mccaustlandm@michigan.gov.

Many hospitals have been visited by the Nurse Consultant/Educator over the last several months. Some staff members have had very interesting ideas or suggestions - You know who You are! - that they were going to send in to be shared with others in the NBS Update. While time constraints are understandable, wouldn't you like to take a few minutes to share your ideas. It is a great way to recognize all of the excellent work that is being done with regard to Newborn Screening, infants, and families. Think about it and share your idea with others.

Information to share continued...

Protection for Infants Begins Before Birth

The Perinatal Hepatitis B Prevention Program through the Michigan Department of Community Health has been in existence since 1991. The focus of the program has been to prevent perinatal transmission of hepatitis B (HBV) virus to infants exposed at birth by identifying hepatitis B surface antigen-positive (HBsAg+) women perinatally and before delivery. Updated recommendations, "A Comprehensive Immunization Strategy to Eliminate Transmission of Hepatitis B Virus Infection in the United States, were released in the Morbidity & Mortality Weekly Report (MMWR), December 23, 2005/54(RR16); 1-23.

The report provides updated recommendations to improve prevention of perinatal and early childhood HBV transmission, including:

- implementation of universal infant vaccination beginning at birth;
- increase vaccine coverage among previously unvaccinated children and adolescents.

Strategies to enhance implementation of the recommendations include:

- 1) establishing standing orders for administration of hepatitis B (hepB) vaccination beginning at birth;
- 2) instituting delivery hospital policies and procedures and case management programs to improve identification of and administration of immunoprophylaxis to infants born to mothers who are HBsAg+ and to mothers with unknown HBsAg status at the time of delivery;
- 3) implementing vaccination record reviews for all children aged 11-12 years and children and adolescents aged <19 years who were born in countries with intermediate and high levels of HBV endemicity, adopting hepB vaccine requirements for school entry, and integrating hepB vaccination services into settings that serve adolescents.

For questions or additional information, call Marcy Smith at 517-335-8122, Pat Fineis at 517-335-9443 or in Southeast Michigan call Sallie Pray at 313-456-4432 or Kari Tapley at 313-456-4431.

Thanks to Patsy Bourgeois, RN, MS, Nurse consultant, for contributing this information.

TAMMY'S TIDBITS ...

The NICU draft guidelines for babies weighing less than 1800 grams is now available for review. Contact Tammy at 517-335-8959 or ashleyt1@michigan.gov if you have not had an opportunity to review this document.

We will be contacting your NICU/SCN in the near future to schedule an appointment with the NICU/SCN Nurse Manager and Neonatologist to review the proposed changes and answer questions. It would be helpful if you would e-mail their contact information to Tammy or Midge at mccaustlandm@michigan.gov. Thanks!

If you would like to receive the NBS Update, have previously requested to be placed on the mailing list, have additions, corrections or deletions, please *complete the information below* and *return this page* to the address listed below.

If preferred, you may also send an e-mail: mccaustlandm@michigan.gov

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A blue oval containing the text "Michigan Newborn Screening Program" in white.

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Program